

NEEDS ASSESSMENT

TECHNICAL ASSISTANCE CONFERENCE CALL

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Arranged by:

Division of HIV Services
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EXECUTIVE SUMMARY

This report summarizes the information presented in "Needs Assessment for Titles I and II," the tenth in a series of nationally broadcast technical assistance telephone conference (teleconference) calls arranged by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA). The report reflects both the content of the presentations and the questions and comments from listeners during the call. The teleconference was broadcast March 26, 1996. More than 1,300 individuals from 220 different sites participated in the teleconference, making this the largest technical assistance conference call so far.

The purpose of the teleconference call was to discuss and clarify requirements and expectations related to needs assessment for Title I and Title II, and describe the needs assessment process itself. The call focused on current and pending legislative requirements and DHS expectations related to needs assessment, components of a needs assessment, a step-by-step process for needs assessment, factors to consider in conducting a needs assessment -- particularly involvement of the PLWH community -- and tools and methods used in needs assessment.

Needs assessment is the cornerstone of the Ryan White planning process. The CARE Act recognizes the role of needs assessment in developing an array of services for people living with HIV and AIDS, and requires Title I EMAs and Title II consortia to assess service needs. Under Title I, the needs assessment process is considered a partnership activity involving the grantee, the planning council, and the community. Title II consortia must demonstrate it has carried out an assessment of need, has developed a plan to meet those needs, including special care and service needs, and that this process has included the participation of individuals living with HIV disease.

The reauthorized Act is more prescriptive in its requirements for needs assessment. For example, under Title I there is more specificity with regard to the needs assessment process and documented need, in terms of both program requirements and funding. Title I grantees are required to participate in the Statewide Coordinated Statement of Need (SCSN) initiated by the agency administering Title II funds, and must demonstrate that services provided in the EMA are consistent with that Statement. Title I grantees must also establish methods for obtaining input on community needs and priorities, including such approaches as public meetings, focus groups, and *ad hoc* panels. Finally, the new legislation defines a measurement of severe need based on certain co-morbidity - such as sexually transmitted diseases (STDs), substance abuse, tuberculosis, severe mental illness, AIDS in previously unknown populations, and homelessness, where such data are available. This measurement will eventually be used to measure and compare severe need across EMAs.

The new legislation further reinforces Title II requirements for needs assessment. Under Title II, services funded at the state level will be required to include a description of how allocation and utilization of Title II funds are consistent with the SCSN, and require that it be developed in partnership with other CARE Act grantees.

DHS has certain expectations related to needs assessment. The needs assessment process is expected to be participatory and inclusive, involving broad representation from the community and people living with HIV (PLWH). Needs assessments should include quantitative as well as qualitative data, and should consider the needs of those in and out of care. The Title I and Title II application guidance provides further clarification on the needs assessment process.

The needs assessment sets the stage for the planning process by identifying the needs in the community, the services available to meet the needs, and the gaps between needs and services. However, the needs assessment can be a meaningless exercise if not planned carefully. The following steps are suggested as a logical approach to the needs assessment process: (1) determine the approach to be followed, (2) develop a timetable and budget, (3) establish a process for community input, (4) select the methods to be used, (5) design the data collection instrument(s), (6) collect all the information, and (7) determine the outcome.

Some basic factors to consider when conducting your needs assessment include: (1) who should conduct the assessment, (2) the length and frequency of the needs assessment process, (3) activities to keep information updated, and (4) who should be targeted in the assessment. Decide from the onset who will be responsible for conducting the needs assessment -- staff, consultant(s), or other individual(s) -- and assure buy-in from all participants. Ideally, needs assessment activities should be ongoing, with new information considered and integrated as it becomes available. However, this does not mean that every component of a formal needs assessment should be repeated with equal frequency, but rather that various components should be updated annually to support priority setting, planning, and resource allocation processes.

Knowing who to target in the needs assessment and then balancing that information are key considerations of the needs assessment process. First and foremost, since the goal is to assess the needs of persons with HIV, PLWHs should be the focus of the needs assessment. Defining the problem from a service delivery perspective makes providers, rather than persons with HIV, the most important group. The needs of the providers and their perspectives must, however, be given weight in the process since they are ultimately part of the solution. The challenge becomes structuring an assessment process that allows for the balancing of both perspectives.

The best way to ensure implementation of your needs assessment is to view it not as an isolated task but as the foundation for a comprehensive effort involving several different tasks including establishing service priorities, allocating resources to specific service categories, and development of a comprehensive plan. When planning the needs assessment, be clear about who will use the needs assessment, how will it be used, what qualitative and quantitative data are needed, and what process will be used for making necessary decisions.

Discuss and agree on a process to be used in setting priorities and allocating resources while you are planning your needs assessment. Then you can be sure that your needs assessment collects, analyzes, and presents data in ways which can make it easy to carry out that process. Be sure that the needs assessment is inclusive: that it generates all the information which will be important in your priority setting and resource allocation. Present information and data separately for important population groups or geographic areas as well as combined to give an overall picture of your service area. Also, present the data in a format and at a technical level appropriate for your users.

A variety of methods can be used in conducting a comprehensive needs assessment, including, but not limited to, review of existing data, surveys, interviews, focus groups, community forums, town hall meetings, public hearings, and other creative approaches to collect needs assessment information. Use more than one approach to data collection, and mix them according to your level of resources and the level of expertise in data manipulation available in your area, as well as your target populations and needs assessment goals. To determine the mix of methods to be used in a needs assessment effort, consider three basic guidelines: What do you want to learn? Who could tell you? and How could you get the information from those people?

Needs assessment data requirements for Title I eligible metropolitan areas (EMAs), including AIDS cases and/or HIV prevalence, are described in the Title I supplemental application. DHS developed the first methodology for estimating local HIV prevalence with a Steering Committee of Title I grantees. However, changes in the AIDS definition have required changes in the methodology. DHS worked with the Centers for Disease Control and Prevention (CDC) to assure that this new methodology is compatible with methods that CDC recommends to HIV Prevention Community Planning grantees. The Division has entered into an agreement with CDC to generate HIV prevalence estimates for all Title I EMAs. Once the estimates are complete DHS will send them to each EMA for review and comparison with local studies of HIV prevalence. If they are consistent with local estimates or if no local estimates are available, grantees will be asked to use them in their fiscal year (FY) 1997 planning process. If they are inconsistent, DHS will discuss them with the grantee and reach a mutually acceptable resolution regarding the estimates to be used. Title II projects should talk with their state Health Departments about what HIV prevalence information is available for their service delivery areas.

TABLE OF CONTENTS

	Page
EXECUTIVE SUMMARY	i
I. INTRODUCTION	1
A. Purpose	1
B. Process	1
II. LEGISLATIVE REQUIREMENTS AND DHS EXPECTATIONS RELATED TO NEEDS ASSESSMENT	2
A. Legislative Requirements	2
B. DHS Expectations	4
III. THE NEEDS ASSESSMENT PROCESS	6
A. Steps in the Needs Assessment Process	6
B. Factors to Consider in Conducting a Needs Assessment	9
C. Implementation Issues	13
IV. INVOLVING PLWHs AND OTHER SPECIAL POPULATIONS IN THE NEEDS ASSESSMENT PROCESS	14
V. NEEDS ASSESSMENT TOOLS AND METHODS	16
A. Using Existing Data	16
B. Surveys and Interviews	18
C. Mixing Methods	19
VI. CONCLUSIONS AND EVALUATION	21
A. Conclusions	21
B. Evaluation	22
APPENDICES	
A. Panelists	
B. Agenda	
C. Using Needs Assessment Results	
D. Summary of Methodology for Estimating HIV Prevalence in Metropolitan Areas	
E. Evaluation Report	

I. INTRODUCTION

A. PURPOSE

This report summarizes the information presented in "Needs Assessment for Titles I and II," the tenth in a series of nationally broadcast technical assistance telephone conference (teleconference) calls arranged by the Division of HIV Services (DHS), Health Resources and Services Administration (HRSA). Included in the summary are both the content of the presentations and the questions and comments from listeners during the call. The teleconference was broadcast March 26, 1996.

The purpose of the teleconference call was to discuss and clarify requirements and expectations related to needs assessment for Title I and Title II, and describe the needs assessment process itself. The call focused on current and pending legislative requirements and DHS expectations related to needs assessment, components of a needs assessment, a step-by-step process for needs assessment, factors to consider in conducting a needs assessment -- particularly involvement of the PLWH community -- and tools and methods used in needs assessment.

The teleconference included panelists from DHS, consultants who have worked extensively with planning councils and consortia to develop and conduct needs assessments, and representatives of grantees with needs assessment experience. (See Appendix A for a list of panelists, and Appendix B for the agenda.)

B. PROCESS

Like the other calls in this series, the teleconference addressed topics and questions submitted by CARE Act grantees, planning council and consortia members, and Ryan White-funded service providers. In addition, listeners had a limited opportunity to ask questions during the call. Participating in the teleconference were more than 1,300 individuals from 220 different sites, making this the largest technical assistance conference call so far.

The format for this conference call included a significant amount of commentary both from DHS, describing the legislative requirements for needs assessment and the importance the Division places on this topic, and from technical assistance consultants. The experiences of several grantees and planning bodies that have carried out needs assessments were used as examples throughout the teleconference to illustrate the needs assessment process. Questions submitted along with participant registration were used to develop the agenda.

II. LEGISLATIVE REQUIREMENTS AND DHS EXPECTATIONS RELATED TO NEEDS ASSESSMENT

Needs assessment is the cornerstone of the Ryan White planning process for Title I and Title II. It is impossible to set priorities responsibly without first understanding the characteristics of the local HIV epidemic, identifying unmet needs for health care and support services, and assessing all the resources that are available locally to meet those needs. Thus, it is clear why needs assessment must be undertaken, and why the Division of HIV Services places such importance on this activity.

A. LEGISLATIVE REQUIREMENTS

The CARE Act recognizes the role of needs assessment in developing an array of services for people living with HIV and AIDS (PLWHs), and requires Title I EMAs and Title II consortia to assess service needs. The original legislation addresses needs assessment in a general and limited manner. Under Title I, planning councils are required to establish priorities and make resource allocation decisions that are consistent with unmet needs. Another specific Title I reference to needs assessment involves intergovernmental agreements with certain political subdivisions within the EMA which, where required, must consider the severity of needs for services in such other jurisdictions. Title I supplemental applications must demonstrate the severe need in an EMA for such supplemental assistance. Under Title II of the original Act, HIV care consortia must develop service plans that address special care and service needs of populations and subpopulations of individuals and families with HIV disease. To receive assistance from the State, a consortium must demonstrate that it has carried out an assessment of need within the geographic area to be served, has developed a plan to meet those needs, and has included in this process individuals living with HIV disease.

ORIGINAL LEGISLATIVE REQUIREMENTS RELATED TO NEEDS ASSESSMENT

Title I:

- Planning councils are required to set priorities and make resource allocation decisions consistent with unmet needs
- Intergovernmental agreements considering service needs of other jurisdictions must be in place
- Supplemental applications must demonstrate severe need

Title II:

- Consortia must develop plans that address special care and service needs
- To receive State assistance, a consortium must demonstrate it has assessed needs and developed a plan to meet those needs, and that PLWHs have participated in this process

The reauthorized Act is more prescriptive in its requirements for needs assessment. For example, under Title I there is more specificity with regard to the needs assessment process and documented need, in terms of both program requirements and funding. The establishment of priorities for allocation of funds must be based on the documented needs of those with HIV, along with other considerations such as the availability of other resources, priorities of HIV-infected communities, and cost and outcome effectiveness. Title I grantees are required to participate in the Statewide Coordinated Statement of Need (SCSN) initiated by the agency administering Title II funds, and must demonstrate that services provided in the EMA are consistent with that Statement. Title I grantees must also establish methods for obtaining input on community needs and priorities, including such approaches as public meetings, focus groups, and *ad hoc* panels. Finally, the new legislation defines a measurement of severe need based on certain co-morbidity - such as sexually transmitted diseases (STDs), substance abuse, tuberculosis, severe mental illness, AIDS in previously unknown populations, and homelessness, where such data are available. This measurement will eventually be used to measure and compare severe need across EMAs.

The new legislation further reinforces Title II requirements for needs assessment. Under Title II, services funded at the state level will be required to include a description of how allocation and utilization of Title II funds are consistent with the SCSN, and require that it be developed in partnership with other CARE Act grantees. HRSA is specifically authorized to provide technical assistance to help develop and implement this new requirement, which still needs further definition. DHS emphasizes that the SCSN is not a comprehensive planning requirement, but a means for coordination across Titles that will jointly be defined between the Division and its constituents.

NEW LEGISLATIVE REQUIREMENTS

Title I:

- More specificity on needs assessment requirements
- Clearer link between needs assessment and Title I decision making
- Participation in the SCSN
- Demonstration that proposed services are consistent with local needs assessment and SCSN
- Definition of “severe need” and measurement of that need across EMAs

Title II:

- Services funded at State level must describe how allocation and utilization of Title II funds are consistent with SCSN

B. DHS EXPECTATIONS

DHS has identified some principles to guide the needs assessment process. DHS and Title I communities collaborated on the development of a baseline needs assessment protocol several years ago, and identified certain guiding principles. These are:

1. Needs assessment should be comprehensive, looking at a broad range of service categories, populations, and geographic areas.
2. Needs assessment should be broadly participatory, including input from special population groups affected by your local epidemic.
3. Needs assessment should include both quantitative and qualitative information.
4. The needs assessment process should be developed and followed in a manner that results in community acceptance of the outcome.
5. The needs assessment should provide the information necessary for priority setting. DHS considers that the entire assessment does not have to be done on an annual basis, but rather updated as necessary.

DHS expectations related to the reauthorization's needs assessment provisions focus on two areas: (1) the process of conducting a community-based needs assessment, and (2) the components of a community-based needs assessment.

Conducting a needs assessment is a partnership activity. DHS expects that needs assessment activities should include planning councils and consortia; Title I and Title II grantees; grantees of other Ryan White Titles; other federal, state and local programs that fund HIV services; private funders of HIV services; providers; community representatives; and people living with HIV both in and out of care. The product of the assessment is to be used by planning bodies to set service priorities and develop comprehensive plans. Needs assessment should be used by consortia in the same manner as Title I planning councils, although it is recognized that there is great variability in consortium efforts. Results of needs assessments should be submitted by Title I grantees to DHS as part of the application process, and by consortium lead agencies to their State funders.

Needs assessment should include quantitative as well as qualitative data, and should consider the needs of those in and out of care. In terms of components of a needs assessment, DHS expects that an assessment includes quantitative data -- epidemiologic data, prevalence estimates, quantification of resources and services -- as well as qualitative data, and should consider the universe of infection and the needs of those in and out of care. In the last several years, there has been a special emphasis on understanding the primary care needs of people with HIV/AIDS and a response to those needs for both Title I and Title II.

The Title I application guidance references several parts of the needs assessment process. EMAs are expected to provide in their Title I applications a description of the epidemic, AIDS cases or HIV prevalence across several variables, and both quantitative and qualitative information about special populations in their service areas -- demographics of each population group, the number with HIV, infection trends, description of the population's unique service needs, what services are currently available, and what other information needs to be considered. Special population groups include injection drug users (IDUs), women, gay and bisexual men, gay and bisexual men of color, and adolescents. DHS requires that grantees provide an update to their needs assessment process. The entire needs assessment does not have to be completed annually, but components should be updated as necessary. Other issues that should be considered in the assessment include co-morbidities, infrastructure and systemic issues, and unique local circumstances. New EMAs are also asked to address access to care and barriers, and their plan to complete a needs assessment. The link of the needs assessment to priority setting and resource allocation across those priorities is key. DHS will further address linkage between needs assessment and priority setting during development of future application guidances, consistent with new reauthorization language.

Guidance for needs assessment under Title II focuses on what is stated in the legislation. DHS expects that the broad components of the needs assessment should be similar to Title I. Title II guidance documents discuss assessing the needs of people with HIV and consideration of other resources. All assessment activities should help in the development of the plan for the use of Title II funds. The National Alliance of State and Territorial AIDS Directors (NASTAD) has prepared a report for DHS analyzing state-level needs assessment and comprehensive planning activities as reported by Title II grantees in their FY 1995 grants; it is available from DHS.

DHS has commissioned a series of six self-assessment tools to assist grantees to evaluate efforts related to a number of grantee and planning body functions. The module on needs assessment is designed to assist planning councils and consortia to assess the effectiveness of their needs assessment process and outcomes in three areas -- completeness of components of the needs assessment, the process followed, and the outcomes of the needs assessment and how this information is used in comprehensive planning and priority setting. The needs assessment module may also be helpful in other ways -- simply reading it gives a good understanding of the elements of a needs assessment, and may help with specific activities such as drafting a scope of work. This self-assessment module is in development and should be ready for distribution in several months.

III. THE NEEDS ASSESSMENT PROCESS

Ryan White Title I planning councils are charged with the responsibility of developing a comprehensive HIV service delivery plan and allocating the necessary resources to implement that plan. Title II consortia are also responsible for planning and developing HIV services in their area. Five basic activities are essential to complete this mission. These are not separate activities to be completed in isolation, but closely interrelated tasks; they include the following:

1. Conducting a needs assessment.
2. Prioritizing those needs and budgeting dollars to service priorities.
3. Developing an HIV services plan.
4. Ensuring that an efficient resource allocation or purchasing system is in place.
5. Evaluating the consortium or planning council processes, the HIV services plan, and the overall quality of services delivered.

This report focuses on the first of these activities: conducting a needs assessment.

A. STEPS IN THE NEEDS ASSESSMENT PROCESS

The needs assessment sets the stage for the planning process by identifying the needs in the community, the services available to meet these needs, and the gaps between needs and services. The needs assessment can be a meaningless exercise if not planned carefully. Often, consortia and planning councils develop extensive sophisticated needs assessment tools and methodologies. They spend great amounts of time, money, and volunteer time only to find that the results don't truly assist them in prioritizing their community's needs and developing a service plan. There is also a tendency to look to the needs assessment to provide the magic formula that will give the consortium or planning council an exact answer on how best to allocate the funds. It is important to keep in mind that the needs assessment is only one of five activities and numerous tools which assist planning councils and

STEPS IN THE NEEDS ASSESSMENT PROCESS

1. Determine the approach to be followed.
2. Develop a timetable and budget.
3. Establish a process for community input.
4. Select the methods to be used.
5. Design the data collection instrument(s).
6. Collect all the information and data.
7. Determine an outcome.

consortia in developing an informed, professional, and responsible plan.

1. Determine the Approach to be Followed

In determining the needs assessment approach to be followed, a series of questions must first be asked. For example, whose needs are you assessing? Who is the target population for your assessment? Is it clients, families, medical providers, psycho-social service providers, consortium or planning council members, people with HIV who are not in the system, the general community, or all of the above? Next you need to ask what programs and services will be assessed -- primary medical services, case management services, emergency programs, home-based care programs, AIDS drug assistance programs, housing programs, support services, or all of the above? Finally, you must ask what aspects of services and program areas will be assessed. What are the different types of needs to be assessed -- access to services, unmet needs, resources that are available, program policies and governmental policies, inter-agency collaboration, the quality of the HIV AIDS interventions, and funding patterns?

2. Develop a Timetable and Budget

First decide on the total length of the needs assessment effort -- start-up and completion dates. Also decide on the specific activities to be completed by certain times; those are your project milestones. Second, determine financial and volunteer resources available for the needs assessment effort and develop a budget incorporating both. Remember that volunteers are a resource that needs to be budgeted; this is especially important for the non-urban consortia. The budget will help define the scope and the methods used for the needs assessment, which in turn will determine methodology.

3. Establish a Process for Community Input

Involving the community is a key requirement of the needs assessment process, and must be given careful consideration to assure broad community participation. Make sure that it is clear who will be involved in the planning process -- key leadership, members of your targeted populations, service recipients, service providers, or all. Decide how the community will be involved in planning and implementing the needs assessment -- through membership in an advisory committee, a working group, a needs assessment oversight committee, and/or other methods. Remember that the community should be involved in all components of the needs assessment process, not just answering questions through surveys and interviews.

4. Select the Methods to be Used

The methods used will vary by site according to the level of resources and other local circumstances. More detailed information related to this step is provided in Section V of this report.

5. Design the Data Collection Instrument(s)

Develop questionnaires and surveys that will help to identify existing resources and services; assess client satisfaction; elicit opinions of key informants; and determine knowledge, attitudes, beliefs, and behaviors of the target populations. Develop questions and protocols for structured groups and interviews that can help to analyze the demand for services.

6. Collect all the Information and Data

Obtain local and state epidemiologic data, morbidity information, substance abuse data, etc. Get CDC reports, as well as reports from other agencies (for example, housing) that may help you get all the information needed for a comprehensive assessment effort. Develop a list of resources currently available in the community, and include AIDS service organizations as well as agencies not solely specializing in HIV/AIDS programs and services.

7. Determine an Outcome

The ultimate goal of the needs assessment is to pull all the data into usable form for comprehensive planning and priority setting. Needs assessment results should be presented in the form of a report. This report should include general background on why the needs assessment was conducted, state the goals of the needs assessment, describe the methods, present the results or findings, discuss implications of the findings, make recommendations for action, and explore the need for further investigation. The report should contain, but certainly is not limited to, the following very specific information. It should include the epidemiology of HIV/AIDS for your community and target populations, a descriptive profile of the community and target populations, and any identified barriers to existing programs and service utilization.

Make the report simple and easy to read; use executive summaries and charts and graphs. It's difficult for consortium or planning council members to try to read a 100 page document. Consider also doing an oral presentation for planning council and consortium members.

B. FACTORS TO CONSIDER IN CONDUCTING A NEEDS ASSESSMENT

Some basic factors to be considered in conducting your needs assessment include: (1) who should conduct the assessment, (2) the length and frequency of the needs assessment process, (3) activities to keep information updated, and (4) who should be targeted in or be the focus of your needs assessment.

1. Who Should Conduct the Needs Assessment

It is important to consider from the onset who will be responsible for completing the needs assessment. Will this responsibility fall upon a needs assessment committee of the

planning body, a consortium or planning council staff person, an outside consultant, or the local Health Department, or will it be a collaboration between staff from community-based organizations and your local health jurisdiction? Needs assessment efforts can be formally led by a staff member or consultant or other individual(s). There are many possibilities.

More important than who is formally assigned to conduct the assessment and to do the work is the active participation of the planning council or consortium. Title II consortia are ultimately responsible for the needs assessment product. Title I planning councils, while not formally charged with conducting an assessment, are required to establish priorities. Since these priorities must be strongly tied to the needs assessment findings, and come out of the process, it is important to involve the planning council as much as possible. Because the needs assessment sets the foundation for all other activities, it is critical that participants buy into both the findings of the assessment and the process through which those findings are realized.

Some groups have made the mistake of expecting that their planning body will simply adopt the findings of an outside consultant. This is a very risky and usually erroneous assumption which can jeopardize and undermine the subsequent steps of the planning process. It is critical that the needs assessment process include a strong role for the planning body or committee members.

2. Needs Assessment Length and Frequency

Ideally, needs assessment activities should be ongoing, with new information considered and integrated as it becomes available. This does not mean that every component of a formal needs assessment should be repeated with equal frequency. At a minimum, conduct some assessment or update annually to support priority-setting, planning, and resource-allocation processes. You want to make sure that it still makes sense to put resources where you have been putting them during the previous year. Consider prevalence estimates annually, since these estimates often serve as a starting point for assumptions and for

numerous assessment activities. In some areas, numbers may not change dramatically from one year to the next; for example, the number of persons that might need a specific service or the resources available for the given service may not change that much in a year. In other cases, you may find that barriers have decreased or increased, or that some other service delivery issue has changed, and it is important to document these changes through focus groups or some other mechanism. Also, it is increasingly important to assess factors that are largely independent of the epidemic. For example, consider how consumers and the HIV service delivery system may be affected by managed care or block grants. An assessment of the health care environment may become as important as quantifying the need for a specific AIDS service.

While the needs assessment should be ongoing -- and thus can potentially last forever -- there need to be logical stopping points that allow you to move on to other planning activities such as priority setting. There is no right answer with regard to how long the needs assessment process should take. However, if the needs assessment was done in a week or two, it was not done correctly. The process could take one to five months annually, depending on the focus and the scope for that year. It is a good idea to set a time frame within which to do the assessment, while at the same time build flexibility into the process. The challenge is to be able to structure the process so that it can be done within a time frame that allows sufficient time both to thoroughly consider needs and to move on to other activities.

COORDINATING A COMPREHENSIVE NEEDS ASSESSMENT AND INVOLVING PERSONS WITH HIV/AIDS: THE MIAMI EXPERIENCE

Miami has Title I and II planning committees to deal with needs assessment. Efforts have included PLWH input from the very beginning -- from community hearings to provide input to the needs assessment planning process, to membership in the planning committees, to participation in the data collection. Miami tries to include at least one-third, sometimes 50%, PLWH representation in both committees and work groups.

Data collection tools include focus groups, town hall meetings, a survey of case managers and their perceptions of clients' met and unmet needs, a client satisfaction survey, and a graphic fiscal analysis of what kinds of funding came into the county. Client demographic and service data from the Public Health Department was also used. Last year, focus groups were organized around ethnic background, and the various target populations. This year the planning committees will look at income levels, and such factors as stage of illness; and change the kinds of questions and ways of asking this information to see if it yields different kinds of information. The planning committees are also getting the HIV Prevention Community Planning Group to incorporate its needs and issues, and working with the University of Miami to incorporate an adolescent longitudinal study to make the needs assessment process truly comprehensive.

Miami has created a year-long timeline of events for the assessment process. Planning for the needs assessment takes two or three months. Then staff -- funded from Title I staff support, Title II, and Housing Opportunities for People With AIDS (HOPWA) funds -- have five months to carry out activities and subcontract certain tasks. Interpreting the results takes about one to two months. When it is time for the prioritization and the allocation process, which is about two or three weeks long, the needs assessment results are available to all members.

3. Activities to Keep Information Updated

Several activities can be carried out to keep needs assessment information updated. With a little structure on the front end, these activities can be built into your plans and require little effort. These activities include abstracting growth in service delivery numbers from the contractors' quarterly or monthly reports, and sharing this information with planning bodies; asking members of your planning bodies to provide information they have obtained through their other non-Title I or II activities; and obtaining data collected through other mechanisms such as focus groups convened by a provider or another committee in your area. All of these data exist outside of your needs assessment process but can be obtained and then incorporated into your process as needed or desired by your planning body.

4. Who Should be the Focus of the Needs Assessment

Knowing who to target in the needs assessment and balancing that information can present challenges. First and foremost, since the goal is to assess the needs of persons with HIV, PLWHs should be the focus of the needs assessment. Do not start by defining your problem from a service delivery perspective, because then the most important group becomes providers rather than persons with HIV. When providers are the starting point, then defining needs in terms of added resources becomes the end; and more resources may not be what are most needed. Starting with consumer input and maintaining a focus on the clients helps to retain the focus on the important problem. Nevertheless, the needs of the providers and their perspective must be given weight in the process since they are ultimately part of the solution. The challenge becomes structuring an assessment process that allows for the balancing of both perspectives. It may be most useful to start with consumers and then structure other parts of the assessment around provider input.

COORDINATING A COMPREHENSIVE NEEDS ASSESSMENT IN A RURAL AREA

The Piedmont Consortium of northeast central North Carolina conducted a comprehensive needs assessment of its nine-county region with a grant from a private North Carolina foundation and Ryan White development funds. The overall cost for the project was about \$20,000-\$25,000, which included a full-time position to coordinate the effort.

A variety of methodologies were used, including one-on-one interviews with infected persons which was the focus of the study. Piedmont Consortium was successful in meeting its goal of interviewing more than 100 HIV-positive persons, one quarter of whom lived in rural counties. This was important as seven of nine counties in the region were rural. It was suggested that existing local resources be used, such as research and statistical facilities at universities or community colleges as well as private companies that conduct research. Gifts and incentives were used to encourage individuals and organizations to become involved in the information gathering process. HIV-positive persons were trained and paid to conduct interviews, and gift certificates were given to the people who completed interviews.

The consortium considered the process as a community-building effort with the ultimate goal of strengthening its service delivery network. Thus, the needs assessment was just one part of the overall goal. The needs assessment effort helped to strengthen partnerships with existing organizations, and created new partnerships that will be useful in making service provision more effective. The consortium recruited a community advisory committee that helped with methodology and process, and spread the ownership of the process beyond just the consortium Board of Directors. The committee helped to increase the involvement of PLWHs in the process. PLWHs were recruited and trained to be interviewers. Informal networks of PLWHs and community-based interviewers were used to help contact hard-to-reach populations. A (Title IIIb) clinic site was used to interview non-consortium clients, another important piece of the process. The consortium also worked with the local homeless shelter; however, it was difficult to attract participants through that site. Human service agencies were offered an in-service training in exchange for providing input.

The part of the process that was possibly the most beneficial was going back and reporting the results to the communities; the consortium did not just "go in, take information, and go away." The findings were also tied to the service provider contracting process. The consortium got a lot of media coverage in the process. It was aggressive in seeking media exposure and making sure that people knew about the needs assessment. One lesson learned was that follow through is probably one of the most important parts of the assessment process.

C. IMPLEMENTATION ISSUES

The best way to ensure implementation of your needs assessment is to view it not as an isolated task but as the foundation for a comprehensive effort involving several different tasks, including establishing service priorities, allocating resources to specific service categories, and developing an HIV services plan. To maximize the needs assessment's usefulness at the decision-making stage, be sure to answer the following critical questions when planning the needs assessment:

1. By whom will the needs assessment be used?
2. How will the needs assessment be used -- what decisions must be made based on its findings?
3. What qualitative information and quantitative data do we need and in what form, with what level of detail, to be able to make these decisions?
4. What process will be used for making these decisions?

Discuss and agree on a process to be used in setting priorities and allocating resources while you are planning your needs assessment. Then you can be sure that your needs assessment collects, analyzes, and presents data in ways which can make it easy to carry out that process. Appendix C provides additional information on using needs assessment data.

In trying to design a needs assessment with implementation in mind, you should think carefully about several important considerations:

- **Be sure that the needs assessment is inclusive** -- that it generates information on specific populations, transmission categories, and geographic areas which will be important in your priority setting and resource allocation. You can't make appropriate decisions about service needs of women or Latinos or gay men of color unless information about these groups is an integral part of the needs assessment.
- **Be sure that information and data are presented separately for important population groups or geographic areas as well as combined to give an overall picture of your service area.** The analysis should present, compare, and contrast the service needs needed by and available to various groups and the entire service area population. If you serve several geographic areas -- perhaps two counties or areas separated geographically by mountains -- then it is essential that your needs assessment provide separate information on the service populations and providers in each of these areas. You may also want specific information about people living with HIV by transmission category. For example, you may need information about injection drug users to help get a sense of the need for substance abuse treatment services. In addition to presenting the information by population or geographic

area, you will also want to combine the data to understand the face of the epidemic over your entire service area.

- **Use consistent definitions.** For example, Table 3 of the Title II guidance and Table 5 of the Title I supplemental grant application guidance specify 32 specific service categories. You will need to use these service categories when you set priorities and allocate resources. So it is important to use the same service categories and terminology as you identify service needs, available services, and service gaps.
- **Be sure to present your needs assessment data in a format and at a technical level appropriate for your users.** Make it easy for the consortium or planning council to find the information it needs for priority setting and resource allocation. Consider variations in technical background and familiarity with epidemiological data. Decide what kinds of charts and graphs are clearest and most appropriate so the entire planning body will generally be participating in the priority-setting process. You want the information to be readily understandable and useable for all members of the planning body.

When you plan your needs assessment, don't see the end product as a needs assessment report. The real end products are a set of service priorities and resource allocations, a defined continuum of care, and a comprehensive plan for HIV services.

IV. INVOLVING PLWHs AND OTHER SPECIAL POPULATIONS IN THE NEEDS ASSESSMENT PROCESS

The involvement of people living with HIV/AIDS in the entire needs assessment design, implementation, and interpretation process is critical. The purpose of the needs assessment is not to identify the needs of the service providers, but the needs of the people living with HIV; accomplishing this requires involving PLWHs. Involving individuals also enhances representation and diversity in the information-gathering process.

While involving PLWHs in needs assessment efforts is a goal that all planning bodies should strive for, rural areas may face some unique challenges with respect to this goal. For example, confidentiality may be a major barrier to meaningful PLWH participation in areas where attitudes about HIV/AIDS and "gay lifestyles" make it difficult for PLWHs to self-identify and participate in consortium activities. Transportation issues may also be a factor in getting PLWHs to meetings and other activities. The box below describes how one rural consortium addresses issues of PLWH involvement.

Including hard-to-reach populations is a challenging aspect of any needs assessment. One way to address the problem is to involve agencies and individuals who deal with hard-to-reach populations in the planning and distribution of the instruments. These can include agencies and individuals that engage in outreach to migrant farmworkers, injection drug users, and the homeless, among other groups. You can accomplish at least two goals by doing this: your

primary goal of getting input from targeted populations and a secondary one, a "buy-in" on the value of the needs assessment from these other agencies. Another way to contact hard-to-reach populations is by including caretakers in your needs assessment. Whether their loved ones were in treatment throughout the illness, only in late stages, or not at all, the caretakers can provide an accurate picture of barriers to care and gaps in services. You may be able to reach caretakers through the local media -- newspapers and radio. Getting information from less visible populations involves an aggressive, active plan tailored to your communities.

INVOLVING PLWHs IN A RURAL AREA: A CASE STUDY

Trinity County is a mountainous area 250 miles north of San Francisco, California with a total population of 14,000, no incorporated cities, and only three state highways and 703 miles of county roads in an area covering two million acres (larger than Delaware and Rhode Island combined). There are no long-term care facilities for PLWHs, and no local doctors or dentists are trained or able to provide basic primary care for PLWHs. Because the only medical services of any consequence are one to three hours away through rugged mountain roads, transportation is a major problem.

Provincial attitudes towards gays and AIDS make PLWHs apprehensive about seeking services and participating in HIV-related activities. Thus, one of the consortium's challenges has been to earn their trust and assure confidentiality -- a challenge it has met well.

The consortium prints flyers with toll-free numbers advertising services, and circulates them so they are readily accessible to the public. It also publishes information about services in local newspapers. Networking with the HIV community and members of the Trinity County Health Care Task Force -- health and human services providers who meet monthly to assure non-duplication of services, and the most efficient use of dwindling dollars -- and using an HIV food bank, which has become a social gathering place for PLWHs, are also ways to get the word out about services. The consortium has made recruiting PLWHs and responding to their needs a priority. Program needs or changes are discussed at consortium meetings and during weekly meetings at the food bank, always allowing PLWHs to "have the last word."

V. NEEDS ASSESSMENT TOOLS AND METHODS

The resources available for conducting the needs assessment activities will vary by locality. Some areas carry out targeted surveys to assess prevalence among different target population groups, while others may participate in larger multi-locality or state assessment activities carried out by other entities. Several needs assessment methods can be adapted by all, regardless of resource level. These include, but are not limited to, focus groups for both providers and persons with HIV, public hearings, targeted surveys, and observation (for example, actually going into a clinic and watching what goes on is an inexpensive way to assess needs and barriers).

As you carry out your needs assessment using whatever resources you have at your disposal, keep in mind that there are no right answers. This knowledge should free you to focus on something more important: your process. If you use a process that is rational and logical, and makes sense to you and the members of your planning body, then that process should lead to what is best for your area. Some factors to consider when using various needs assessment tools and methodology are described below.

A. USING EXISTING DATA

Title I EMAs are required to provide HIV/AIDS prevalence information as part of their Title I supplemental application. The Title I needs assessment protocol first appeared as a requirement in Title I Supplemental Grant Application for fiscal year (FY) 1994. The Division of HIV Services worked with a Steering Committee of Title I grantees to develop the first methodology for estimating local HIV prevalence. DHS also worked with CDC to assure that the methodology developed for Title I is compatible with methods that CDC recommends to HIV Prevention Community Planning grantees.

The methodology relied on local AIDS incidence as reported to CDC and an assumed relation to national HIV prevalence estimates to derive local prevalence estimates. In FY 1995, new grantees were asked to use the FY 1994 methodology, and continuing grantees to update their prevalence estimates from the previous year. However, by FY 1995, it was clear that the methodology would need to change because of changes in the AIDS definition that occurred in 1993. In FY 1996, Title I grantees were required to complete simple tables of local AIDS incidence. While these tables are not ideal, because they represent only the AIDS population and not other people with HIV, they can still provide useful information.

HIV prevalence estimate: is an estimate of the number of people living with HIV within a given Title I EMA

AIDS incidence: is the number of people/AIDS cases diagnosed for a given period of time

In preparation for the FY 1997 planning process, DHS entered into an agreement with CDC to develop a new methodology for determining HIV prevalence in Title I EMAs. Considerations in selection of the new methodology included identifying a sound methodology that uses nationally available data, ensuring compatibility with CDC prevention planning initiatives, ensuring that expertise and burden requirements imposed on grantees by the methodology are reasonable, while at the same time keeping in mind the limited epidemiological resources at the Division of HIV Services.

The new methodology -- which is detailed in a CDC document entitled *Simple Methods for Estimating HIV Prevalence* -- starts with data from the Survey of Childbearing Women (SCBW) and from AIDS surveillance. The box below lists the five steps in making prevalence estimates for adults and adolescents in EMAs. A more detailed outline of the procedure is included in Appendix D.

STEPS FOR ESTIMATING HIV PREVALENCE IN EMAS

1. Estimate prevalence among women ages 15-44 who have not been diagnosed with an AIDS-defining opportunistic illness (AIDS-OI).
2. Extend estimate to all adult and adolescent women, using AIDS surveillance data.
3. Estimate HIV prevalence among adult and adolescent men.
4. Estimate number of infected adult and adolescent men by race/ethnicity and risk group.
5. Estimate number of infected adult and adolescent women by race/ethnicity and risk group.

After finalizing the new methodology, DHS was concerned that it might present difficulties for some EMAs with limited epidemiological resources. The Division entered into an agreement with CDC to generate HIV prevalence estimates for all Title I EMAs. Once the estimates are complete, DHS will send them to each EMA for review and comparison with local studies of HIV prevalence. If they are consistent with local estimates or if no local estimates are available, grantees will be asked to use them in their FY 1997 planning process. If they are inconsistent, DHS will discuss them with the grantee in question and reach a mutually acceptable resolution regarding the estimates to be used.

Title II consortia may wish to talk with their State Health Departments about what HIV prevalence information is available for their service delivery areas.

B. SURVEYS AND INTERVIEWS

Surveys and interviews are two of the most commonly used methods of data collection in the needs assessment process; however, keep in mind that needs assessment is not synonymous with survey and interview, and many other methods are available. In conducting a scientific survey of PLWHs, it is most important to understand what the population universe is -- that is, what the epidemic looks like in the area. Often, published AIDS data tend to focus on national data, or data from the AIDS epicenters. This is not particularly helpful for EMAs like Dallas, for example. The Dallas EMA's caseload does not look like that of Newark, New Jersey, or New York, and it probably won't ever look like them. EMAs need to be aware of these data differences and adapt their surveys accordingly. EMAs that do not have sufficient resources should use resources at the CDC or other sources to get an accurate picture of what the EMA looks like with respect to race, gender, and modes of transmission, if these data are available. Then they will be able to target their surveys or interviews to reflect the local face of the epidemic.

Having more information available at the beginning of the process is better for conducting scientific surveys, because it will be easier to set quotas and use cluster sampling in order to fill those quotas. You can involve points of care as well as existing service agencies in reaching desired population groups. This is particularly useful when you know that particular service agencies have a specific clientele which may be outside the reach of many points of care. You can also request help from community activists to bring in homeless people and individuals who may be outside the service system.

The number of surveys and interviews that you carry out is only as important as whether or not the sample is representative of the people from whom you want to hear. Construct the survey and/or interview instruments based on the domains of information --knowledge or behavior -- that your sample can provide to you. Spread out your domains across methods and participant types. Don't ask everybody everything. Narrow down each instrument to one or two domains only. Consult a survey construction expert, and pilot test and revise the instruments. With regard to local versus statewide instruments, if no local resources exist to help you develop your own instrument, go ahead and adapt a statewide instrument to meet your local needs.

A CASE STUDY IN USING MARKET SURVEY RESEARCH: DALLAS, TEXAS

The Dallas EMA engages in a very specific type of needs assessment developed over the past five years. It is based on market survey research. Dallas believes that the best way to get information concerning the needs of PLWHs is to ask them directly. It doesn't consider that focus groups have provided very useful information in the past. In the beginning, the Dallas needs assessment team used a combination of survey research techniques and focus groups, but it became obvious that respondents were often unwilling to criticize providers upon whom they depended for services.

Approximately 750 people were contacted during the previous needs assessment. This year the EMA will conduct a needs assessment of approximately 500 PLWHs in the greater Dallas area, including the surrounding rural counties that are part of the EMA, as well as approximately 200 caregivers, at a cost of approximately \$36,000 -- primarily resources from a partnership with the EMA and the University of Texas at Dallas.

The assessment team has found it very useful to ask people within the service system what sorts of needs/factors bring them to the service system, and facilitate their using services both at the current time and in previous experiences coming into the system. Dallas has found that this is a very important way to address the needs of special populations in that community. The major lesson learned is that it is possible to do a scientific survey market research type approach and to get a high level of cooperation from PLWHs. The response rate generally exceeds 95%.

The assessment team has found that most people are happy to express their views, and their affiliation with a university generates a certain level of trust. Establishing trust with interviewers, research leaders, the EMA, and the planning council is very important; and it has been very useful for Dallas in getting analyses which help to develop understanding about what PLWHs in the community want, how the services are delivered, and whether or not needs are being met.

C. MIXING METHODS

A variety of methods can be used in conducting a comprehensive needs assessment. In addition to the already mentioned methods of reviewing existing data, surveys, interviews, and focus groups, consider community forums, town hall meetings, public hearings, and more creative approaches to collect needs assessment information. Use more than one approach to data collection, and mix them according to your level of resources and the level of expertise in data manipulation available in your area, as well as your target populations and needs assessment goals.

To determine the mix of methods to be used in a needs assessment effort, consider three basic guidelines:

- What do you want to learn?
- Who could tell you? and

- How could you get the information from those people?

Based on those guidelines -- what, who, and how -- determine the methods to be used.

A CASE STUDY IN MIXING METHODS: VENTURA COUNTY, CALIFORNIA

The Ventura County HIV Care Consortium conducted a needs assessment using three different methods, each with its own protocol and data collection instrument; and in all cases all responses were kept confidential. The first method employed was focus groups conducted by an independent consultant since people are reluctant to complain to the service providers. The focus groups allowed the consortium to obtain rich data from individuals who had seen the course of HIV disease, as well as those at high risk or already infected with HIV. Focus group participants included caregivers and survivors of people with AIDS who could share their personal experiences in dealing with the disease - health care providers, as well as friends and family members. They also included youth, HIV-positive drug-abusing women, gay men, and other special populations. All focus groups were conducted separately, and on a level playing field; there weren't any superiors sitting in with workplace subordinates, or other similar situations. The consortium limited the questions to only three per focus group, and it took just over an hour to complete each focus group.

The second method used was key informant interviews, also conducted by an independent contractor/interviewer. The interviews also yielded rich data from individuals who had a extensive knowledge of a particular area such as housing, or medicine, or dentistry.

Key informants included agency directors and high-level community members who would not be appropriate for focus groups because of time or other constraints. The interview instrument was completely open-ended, with questions to be coded later, and it took about one hour to complete.

The third method used was client surveys -- paper-and-pencil surveys administered at service organizations. The survey itself looked quite long, but there was a lot of white space and it only took about five minutes to complete. It was very easy to read and complete. Clients were asked only three basic questions: In the past six months did they need a particular service? If yes, did they receive the service. If no, why not? The why nots were closed-ended responses that participants could just choose an appropriate answer.

A general notion to keep in mind is that needs assessment will never be perfect. There will always be the need for more information. You just need to decide when "enough is enough." Recognize that your local needs assessment is an evolving effort and that each year you will add information that you need and want for better local decision making. Remember that DHS has resources available to help your needs assessment process -- Project Officers, consultants through the Technical Assistance Contract, and other resources.

VI. CONCLUSIONS AND EVALUATION

A. CONCLUSIONS

The CARE Act recognizes the essential role of needs assessment in developing an array of services to people living with HIV and AIDS, and requires Title I EMAs and Title II consortia to assess service needs. While Title I assigns responsibility for needs assessment to the grantees, planning councils are partners in the needs assessment process, since they are required to set priorities and make service area resource allocation decisions consistent with unmet needs. Under Title II, consortia must assess needs and develop a plan to meet those needs, with the participation of PLWHs. In addition, DHS has certain expectations related to needs assessment, including that the needs assessments be comprehensive, that it include quantitative as well as qualitative data, that it consider the needs of those in and out of care, and provide the information necessary for priority setting. The needs assessment process is expected to be participatory and inclusive, involving broad community and PLWH representation.

The needs assessment sets the stage for the planning process by identifying the needs in the community, the services available to meet the needs, and the gaps between needs and services. Some basic factors to consider when conducting a needs assessment include: who should conduct the assessment, the length and frequency of the needs assessment process, activities to keep information updated, and populations that need to be targeted. The following steps are suggested as a logical approach to the needs assessment process: (1) determine the approach to be followed, (2) develop a timetable and budget, (3) establish a process for community input, (4) select the methods to be used, (5) design the data collection instrument(s), (6) collect all the information, and (7) determine the outcome.

The best way to ensure implementation of your needs assessment is to view it not as an isolated task but as the foundation for a comprehensive effort also involving setting service priorities, allocation of resources to specific service categories, and development of a comprehensive plan. When planning the needs assessment, be clear about who will use its results, how they will be used, what qualitative and quantitative data are needed, and what process will be used for making these decisions. Discuss and agree on a process to be used in setting priorities and allocating resources while planning the needs assessment. Then be sure to collect, analyze, and present the data in ways which can make it easy to carry out that process. Be sure that the needs assessment generates needed information in formats appropriate for the priority setting and resource allocation processes.

A variety of methods can be used in conducting a comprehensive needs assessment. Use more than one approach and mix them according to your level of resources, the level of expertise in data manipulation available in your area, target populations, and needs assessment goals. To determine the mix of methods to be used in a needs assessment effort, consider three basic guidelines: What do you want to learn? Who could tell you? and How could you get the information from those people?

It's impossible to make resource allocation decisions without first understanding the characteristics of the local HIV epidemic, identifying unmet needs for health care and support services, and assessing all the resources that are available locally to meet those needs -- this can only be done through a comprehensive, participatory, ongoing needs assessment process.

B. EVALUATION

Participants in each teleconference call are encouraged to complete brief written forms asking for evaluation feedback, suggestions/comments, and recommendations for follow-up. These forms are sent to the national CARE Act technical assistance provider for analysis. Fifty-seven evaluations were received from conference call participants; the full evaluation report is included as Appendix E. Major results are summarized below.

Overall, the teleconference received high ratings (3.6 on a scale of 1 to 5). Listeners had especially positive opinions regarding the usefulness and timeliness of the conference call content, and commended its organization. However, a number of respondents (18%) were concerned that there were too many speakers trying to cover too many topics, thus the information was presented too quickly and important topics were skimmed over, and there was little time for questions from the listeners.

There was positive feedback about having grantees present their experiences, and especially including speakers from rural areas. Respondents' comments indicated a desire for more preparation prior to the conference call, and more timely follow-up afterwards. Twenty-three percent of respondents asked for more extensive materials prior to conference call to prepare questions and follow along during the presentations.

Respondent comments highlighted the importance of the teleconference reports. A number of respondents made favorable observations regarding the usefulness of the report; 30% of respondents stressed the importance of follow up report summaries -- 12% of those asked that reports be distributed faster.

APPENDIX A: PANELISTS

FACILITATOR

Jon Nelson, Chief, Planning and Technical Assistance Branch, Division of HIV Services

From the Division of HIV Services (DHS):

Anita Eichler, Director

Steven Young, Chief, Eastern Services Branch

Andrew Kruzich, Deputy Chief, Planning and Technical Assistance Branch

Wendell Pope, Deputy Chief, Service Documentation Branch, DHS

Consultants:

Donna Yutzy, Sacramento, CA

Erica Salem, Chicago

Cristina Lopez, MOSAICA, Washington D.C.

Grantee Representatives:

Susan Sachs, Piedmont Consortium, North Carolina

Joey Wynn, Miami Planning Council

Mo Lovely, Chair, Shasta-Trinity AIDS Consortium, Weaverville, CA

Greg Thielemann, Professor of Political Economy at University of Texas at Dallas and Consultant to the Dallas EMA

Diane Seyl, Ventura County Public Health Services, Ventura County, CA

Dr. Elizabeth Trebow, Manager Health Statistics, Ventura County Public Health Department, Ventura, CA

APPENDIX B

AGENDA

AGENDA

“NEEDS ASSESSMENT FOR TITLES I AND II”

**Technical Assistance Conference Call
Tuesday, March 26th, 1996 1:00 - 2:00 PM Eastern**

I. Opening Statements -- An Overview of Needs Assessment for Titles I and II

II. Requirements Related to Needs Assessment

A. Legislative Update

- What are the current legislative requirements related to needs assessment?
- What are the pending legislative requirements related to needs assessment?

B. DHS Expectations

III. Needs Assessment Process

A. Fundamentals

- What are the components of a needs assessment? (Donna Yutzy - 3 mins.)
 - What questions does the needs assessment address?*
 - What do you intend to do with the needs assessment?*
 - How do you assess all needs - medical and psychosocial?*
 - What are the different types of needs?*
 - How do you integrate all affected populations into the needs assessment?*
 - How do you integrate epidemiological data and community input data?*
- Who should conduct the needs assessment?
- How often should a needs assessment be conducted?
- How long should the needs assessment process take?
- What activities should be done to keep information updated?

- ◆ Who should be targeted in the needs assessment?
Who should be the focus of the needs assessment? What weight should be given to responses by providers? consumers? others?
- How can a structure and support for implementation be built into the development of the needs assessment itself?
- ◆ How can the needs assessment be funded?
In a tight budget, from where can you allocate funding resources to conduct a needs assessment? How do you conduct ongoing needs assessment with limited resources in terms of budget, personnel, and resource materials?
- What should be the anticipated cost‘?
- How do you conduct a complete, accurate, needs assessment that will cover a broad area encompassing much rural area?

B. PLWH Issues

- ◆ How can you ensure maximum consumer response?
- ◆ What are some ways to reach PLWHs who are not integrated into care services systems?
- ◆ What are some ways to reach “hard to reach” populations -- homeless, youth, illiterate populations, migrant workers, injection drug users.etc.?
- ◆ What are some ways to reach rural consumers?
- ◆ How can consumers be used as interviewers?
- ◆ How can you recruit PLWHs to take surveys or participate in the needs assessment process?

QUESTIONS FROM AUDIENCE

IV. Tools / Methods

A. Existing Data

How do you use HIV prevalence data and other key secondary data sources?

B. Methodology Mix

*Discuss methodology mix -- mailed questionnaires, focus groups, telephone interviews, in-person research **among** providers.*

C. Surveys / Interviews

How many interviews should be conducted? What should the sample size be?

How do you make the needs assessment instrument as concise as possible, eliminating extraneous questions?

Is it better to devise the needs assessment instrument locally or use a standard one statewide?

QUESTIONS FROM AUDIENCE

V. What Support is Available to Help with the Needs Assessment

- Are there existing needs assessments and needs assessment tools available as resources?
- Is there a mechanism by which areas and planning bodies can share their needs assessments with others?
- What guidance is available from DHS?

VI. Closing Statements

APPENDIX C

USING NEEDS ASSESSMENT DATA

USING NEEDS ASSESSMENT DATA

Prepared by Emily Gantz McKay, President, MOSAICA, for the Division of HIV Services' Technical Assistance Contract

The needs assessment conducted by an HIV planning council or consortium provides information needed for much of its deliberations and decision making, including priority setting, allocation of resources to service areas, coordination with other funding streams, and comprehensive planning. The practical value of the needs assessment for these purposes -- as well as for broader community uses -- depends upon appropriate planning, information collection, analysis, reporting, review, and utilization. The effective use of needs assessment results requires careful planning, analysis, and report preparation, and a shared commitment to making decisions using the information base which needs assessment can provide.

Following are some hints for making sure your needs assessment is maximally useful in the Ryan White Comprehensive AIDS Resources Emergency (CARE) Act decision-making process. and in strengthening the network of HIV/AIDS services in your service community. They can be used regardless of who plans and implements the needs assessment; the needs assessment "study team" may be paid expert consultants or a group of planning body members, grantee staff, and/or community volunteers. If paid consultants are used, you might have a task force or committee of planning body and grantee personnel to oversee their work; if a planning body/grantee team does the needs assessment, the entire planning body may be involved in oversight. Whatever the structure, a "study team" is likely to take primary responsibility for doing the needs assessment, but the entire planning council or consortium will need to participate in design, analysis, and oversight. The information below will help you do this successfully.

AS PART OF THE PLANNING PHASE:

1. Define and agree upon the uses of your needs assessment early in the process. Those sponsoring the needs assessment, those carrying it out, and those who will use its results for planning and decision making should be in agreement, especially about needs assessment "endpoints, " the specific information to be generated or updated this year and the form in which it will be provided. Once you know what you need, you can be sure that the needs assessment process is designed to generate this information. For example:

- **What are the major questions to be answered and the "bottom line" information requirements for this needs assessment?** Considering the priority-setting process, what are the most critical information needs? What information must be included regarding specific populations, transmission categories, and geographic areas?
- **What data must be analyzed and presented separately, as well as combined?** Are separate data needed by population, transmission category, and/or geographic area?

- **How will services be categorized?** In priority setting, you will probably use the service categories included in application guidances. Using these categories in the needs assessment avoids confusion when using needs assessment results.
- **What specific populations will be defined and targeted, and what level of information will be sought about each of these populations?** Sometimes, you may need to be sure that particular racial/ethnic groups or other defined high-risk populations are identified for targeting and that they are considered “primary” targets for all information collection, or they may otherwise be underrepresented.

2. Determine the decision-making process and steps you expect to use in setting priorities and allocating resources. Only by doing this before the needs assessment can you be sure your needs assessment will generate the information you need in the form in which you need it. For example, the needs assessment may need to:

- Describe current statistics and trends in HIV seroprevalence and AIDS cases among specific populations, so that the planning council or consortium can predict the future characteristics of the epidemic in your service area.
- Describe the range of services in particular communities serving particular populations, to enable the planning body to understand the existing service system and determine service gaps for particular geographic areas and populations.
- Include information about service availability, accessibility, and quality from varied perspectives -- not only service providers and current clients, but also those with HIV/AIDS but not receiving CARE Act services, various target and population groups such as women, gay men of color, other minorities, injection drug users, the homeless, etc. -- to give the planning council or consortium a broad understanding of perceived service needs and gaps.
- Identify other funding streams and the extent to which they are and will continue to support needed services, so you can use CARE Act resources to fill service gaps and not duplicate efforts.

3. Be sure the kinds of analysis planned will generate the information needed, in an appropriate format. Often, those designing the needs assessment will prepare not only questions to be answered and a report outline, but also “dummy tables” which indicate the kinds of statistical analyses they will generate -- for example, presenting certain kinds of statistical data both by geographic area (e.g., by county, by central city versus other parts of the metro area or eligible metropolitan area), and by population group (e.g., by race/ethnicity, by special population group). Developing a list of comparisons or a pile of dummy tables -- and reviewing it as a group -- can be very important to be sure that your planned analysis can provide the kinds of charts or narrative discussions needed to identify service needs and gaps and set service priorities. Taking a practical approach can help you get a clear idea of what information will be available to you in what form; for example:

- a. Review the major questions to be answered by the needs assessment, and be sure they are fresh in your mind.
- b. List the more specific questions or kinds of analysis you feel you need in order for those major questions to be answered.
- c. Review the questions that will be answered by each table or type of analysis being planned.
- d. Compare the Lists b and c, and see if any **important information** you need is missing from the list of questions that the proposed analysis will answer. Discuss whether that information can be generated -- and if not, why not.

This process will help assure that the analysis process generates the information needed to answer certain questions directly; generate projections such as the future extent, distribution, and impact of HIV/AIDS among defined populations; describe the service system and identify gaps; and enable the planning council or consortium to carry out its decision-making responsibilities.

4. **Plan to share results with the community, and show how the needs assessment will provide community benefits.** Develop a plan for using results to set priorities, allocate resources, prepare or update a comprehensive plan, and make positive changes in the organization and delivery of HIV/AIDS services -- and share this plan with communities from whom you need cooperation and information. Many low-income and minority communities have been “studied to death,” so obtaining cooperation requires that your needs assessment team be able to demonstrate that the process will lead to improved services for people living with HIV/AIDS (PLWHs) and their families. Community groups may also want access to the report and perhaps some specific data from the needs assessment, for their own planning and resource development efforts. You may even find that some other community group is also contemplating a needs assessment process, and collaboration may be feasible.

DURING THE INFORMATION COLLECTION PROCESS :

5. **Be sure that the “study team” consults with the full planning body regularly.** Even if you have a committee or task force responsible for the needs assessment, the entire planning council or consortium should hear progress reports from this group during any major needs assessment effort. This is important whether the “study team” consists of planning body members and grantee staff or paid external consultants. The responsible committee or task force should monitor the process to be sure that there has been no change in the breadth of the information collection process, and that needed information will be obtained, analyzed, and reported as planned. If the task force is conducting the needs assessment directly, it should regularly share progress and problems with the full planning body as its oversight group. Be sure no changes affecting results are made without careful review by the planning council or consortium.

ONCE THE INFORMATION HAS BEEN COLLECTED :

6. **Be sure that both quantitative and qualitative information are adequately analyzed and presented.** Sometimes, if analysis plans are not completed and reviewed prior to data

collection, there is insufficient time to fully analyze and interpret results in time for use in priority setting -- or to check and refine the interpretation of the findings. Qualitative information is very important, but often takes more time to analyze than quantitative data and requires culturally sensitive and knowledgeable review. Strive for a multicultural analysis team. If the “study team” consists of planning body and grantee personnel, remember that community knowledge is an important complement to analytic skills. Be sure that representatives of various communities -- ideally, planning council or consortium members from diverse population groups -- see the data very early in the analysis process, to be sure that assumptions and interpretations are accurate. Build in time for the entire planning body to review the initial results, and urge members knowledgeable about diverse population groups to provide active input. Be sure that sufficient time is allocated after the initial presentation for further analysis and revisions if you find problems.

7. **Be sure findings are presented in a format and level of detail which is understandable and useful for all planning body members.** Make sure it is easy for the consortium or planning council to find the information needed for priority setting and resource allocations. Consider variations in technical background and familiarity with epidemiological data. Be sure you are comfortable with the format to be used for presenting information before the assigned writers have begun preparing the report. Ask your “study team” to make a presentation to the full planning body which outlines the report; ask that this be done by someone who has good presentation skills. Ask that person to bring the proposed narrative report outline and samples of the major types of analysis tables, charts, and narrative formats that will be used, and to explain them to the full planning council or consortium. If you feel any of them are unclear and will be very difficult for non-researchers on the planning body to understand and use for decision making, ask that the formats be clarified and revised. If the narrative analyses are at an excessively technical level, ask that they be revised. Consider putting some data tables and other very detailed information into technical appendices which can be used by researchers, but need not be read by other users.

8. **Have the “study team” continue to consult with the full planning council or consortium stages in the report-preparation phase.** First, request preliminary findings and provide reactions. Then be sure you approve the report outline. Finally, request a draft report for review before it goes to anyone outside the planning group or is used for any decision making. Get member comments individually as well as having a review meeting. A major purpose of the needs assessment report is to provide planning councils and consortia with the information needed, in the form needed, to make some important decisions regarding service priorities and allocation of CARE Act resources. If the report does not meet these requirements, making these decisions will be very difficult regardless of the quality of the needs assessment effort -- so take the time to ensure a useful report.

9. **Encourage creative formats designed to support the decision-making process.** For example, one of the requirements of the needs assessment is to identify unmet HIV/AIDS service needs. One aspect of this assessment is determining where certain kinds of program are operating, such as where primary care facilities are located, and the service areas of AIDS service providers. One visual way to present this information is by mapping the locations of AIDS service providers and their service areas. Moreover, you can use different colors, symbols, or patterns to show primary care and supportive services or programs focusing on various populations. To assess accessibility of primary care providers or other facilities, also map public transportation and

parking facilities, and mark those programs that go to participants or provide transportation to their centers.

ONCE THE REPORT IS COMPLETE :

10. Prepare summary materials for use in using and sharing results. Be sure some clear and effective graphics summarize study findings. Summaries on large pads (“newsprint”), overhead projections, and large charts are all appropriate; you want to be able to illustrate and call attention to major findings as clearly and effectively as possible. Very effective charts can be generated on a personal computer.

11. Carefully review what the needs assessment seems to tell you about HIV/AIDS in your service area. Make this a major topic of discussion at one or several planning council or consortium meetings. Divide the presentations by topic -- trends in the epidemic, service needs and demands, existing services, service gaps, etc. -- and by geographic area and population as appropriate. Arrange for specific discussions of what information the needs assessment provides related to issues you believe will be especially important in your decision-making processes; the following are just a few examples:

- Based on the planning body’s concept of a necessary set of core services (a core “continuum of care”), what needed services exist within the service area? which are missing? How do availability and accessibility vary based on geographic location?
- What are the major service gaps in terms of categories of services identified in the Division of HIV Services (DHS) application guidances?
- What are the differences in perceived service needs for current clients versus those not receiving CARE Act services? for different population groups?
- What other funding streams are helping to support services, and what changes are projected in these funding streams?

12. Give each member of the planning body a specific new perspective to take in reviewing the needs assessment with an eye to priority setting. People tend to view situations from their own perspectives. Ask specific individuals to review the needs assessment from the perspective of a particular service population, such as various racial/ethnic groups, women, gay men of color, injection drug users, the homeless, and other groups. Be sure each assigned perspective is different from those usually taken by the member based on his/her affiliations. but not so different that the member will find it difficult to assume the assigned perspective. Then ask for a similar review from members’ usual perspectives. This process helps members see perspectives other than their own, and provides a check on the completeness and accuracy of the information available.

13. Be sure that important community factors are considered and understood in the analyses of the epidemic. Add updated or culturally-focused information to the needs assessment results. For example, you may be familiar with the geographic trends in a particular community. Perhaps Latino or African American families are moving into an area previously occupied largely

by older White non-Hispanics, and different AIDS services are now needed in that community. Perhaps a service provider has just received a major new foundation grant for AIDS services -- or perhaps a major grant has ended. Planning body members should review the needs assessment to be sure these trends or situations were considered.

14. Question assumptions and identify factors which might affect the appropriateness of services for a specific population. People tend to make assumptions based on their knowledge, experience, and affiliations. It is important to question assumptions made in the needs assessment or by the planning body. PLWHs from varied communities can help with this process. For example, they might identify a gap in primary care services if data indicate that certain clinics include no gynecologist and no general practitioner or internist with specific training on women and AIDS. They might question the ability of a case management provider with no bilingual personnel to adequately serve Latinos. Such questions provide valuable input to the priority-setting process.

15. Report back to the community. Be sure to make and implement a plan for publicizing results, including wide dissemination, media attention, and extensive efforts to report back to various segments of the community about findings and their implications. The needs assessment was developed through obtaining a broad range of community perspectives; the results needed to be presented to the community, not just to the planning body. Members of the needs assessment committee or the entire planning council or consortium should share major findings with various neighborhoods and populations, and PLWHs have a special role to play -- through speaking at community meetings or other events, providing information to mainstream and specialized media, and making themselves available to community groups wanting needs assessment information.

16. Encourage the broad use of needs assessment results. The needs assessment has many uses beyond the CARE Act planning and decision-making process. It can be a valuable tool for convincing other funders, public and private, of the need for additional resources for HIV/AIDS services. It also provides a basis for cooperative action by service providers, to better meet service needs, fill in gaps, and avoid duplication of effort. It can encourage cooperation among public, private, and community sectors. A needs assessment can lead an organization to modify its missions or priorities, and helps ensure that limited resources are used appropriately. It provides a sound basis for community input to policies, programs, and funding decisions to more equitably serve the entire community; the information provided by the assessment helps to develop consensus on priorities for PLWH advocacy, and makes it hard for decision makers to deny that community concerns are real and serious. Many human service agencies and PLWH groups find themselves speaking for their neighborhoods, interpreting their needs and concerns to funders and to the larger community. Such actions typically reflect many years of community involvement, but they can be strengthened by use of the "hard data" which can be generated by the needs assessment.

APPENDIX D

SUMMARY OF METHODOLOGY FOR ESTIMATING HIV PREVALENCE IN METROPOLITAN AREAS

ENCLOSURE

Summary of Methodology for Estimating HIV Prevalence in Metropolitan Areas

HRSA will provide each **EMA** with estimates of HIV prevalence (the number of living HIV-infected persons, **including** persons already diagnosed with AIDS) within each of certain pre-defined categories. These categories are defined by various combinations of sex, **race/ethnicity**, age, and stage of HIV-related disease.

The estimates of HIV prevalence will be calculated by the Centers for Disease Control and Prevention (CDC) using data from the Survey in Childbearing Women (SCBW) and from AIDS surveillance. An outline of the procedure is described below. Note **that** essentially the same procedure will be used for every **EMA**. As a result of the large number of **EMAs** and the short time period available to do these calculations, it will not be possible for CDC to consider additional data which may be relevant for making these estimates.

Outline of the estimation procedure

The major steps in making these prevalence estimates for adults and adolescents in **each EMA** are described below. For each category, CDC expects to provide a point estimate. While it would be desirable to provide a **plausible** range instead, it is difficult to **estimate** the uncertainty in each estimate. In addition, the point estimates should reflect the estimated relative number of infected persons in various categories (i.e. indicate which categories have relatively many or relatively few infected persons), which should be adequate for policy purposes.

1. Estimate HIV prevalence among women aged 15-44 years who have not been diagnosed with an AIDS-defining opportunistic illness (AIDS-01). These estimates are based on the SCBW and U.S. census data.
2. Extend this estimate to **all** adult and adolescent women, using data from AIDS surveillance. The AIDS surveillance data are used to estimate the **proportion** of **all** living infected women who are aged **15-44** years, and to estimate the number of living infected women already diagnosed with an AIDS-01.
3. Estimate **HIV** prevalence among adult and adolescent men. These estimates are based on the estimated number of living HIV-infected women who have not developed an AIDS-01 (calculated in the previous step), and on AIDS surveillance data. The AIDS surveillance data are used to estimate the male-to-female ratio of living infected persons who have not developed an AIDS-01, and the number of living infected men **already** diagnosed with an AIDS-01.
4. Estimate the number of infected adult and adolescent men by **race/ethnicity**, and by

risk group. Make similar estimates for women. Both for men and for women, these estimates are based on using the proportions of recently diagnosed **AIDS** cases (by race/ethnicity or by risk group) to estimate the corresponding **proportions** of living infected adults and **adolescents**. For example, the **proportion** of all living infected adult and **adolescent** men who are white is assumed to be the same **as** the corresponding proportion in recently diagnosed **AIDS** cases.

Note that **AIDS** surveillance data are used in two ways. One is to estimate the number of living infected persons diagnosed with an **AIDS-OI**. The other is to estimate proportions of infected persons within certain categories.

For some **EMAs**, we will use data from a larger area in the same state to make these estimates. We will use this procedure for **EMAs** in states that do not provide **county-level SCBW** data to CDC (e.g. Arizona and Colorado), as well as for **EMAs** with very few seropositive women in the **SCBW**. For these **EMAs**, we will **estimate** the number of infected women of childbearing age for the larger area. We will then estimate the proportion of these women who lived in the **EMA** as the corresponding **proportion** of **AIDS** cases from the larger area. We will **also** base other estimates of proportions on the proportions of **AIDS** cases diagnosed in the larger area.

Estimates of the number of living infected children (aged less than **13** years) are based on other methodology developed at CDC. This methodology is based on data from **AIDS** surveillance but is too complicated to describe here.

CDC has distributed a document, "Simple methods for estimating **HIV** prevalence" (dated June 1995) that contains somewhat more detail about these methods. CDC sent copies of this document, which was written to assist in the community planning process, to appropriate state and city public **health** personnel. Copies can **also** be obtained from Wendell Pope in the **HRSA** Division of HIV Services at 301-443-0654.

APPENDIX E:

EVALUATION REPORT

RYAN WHITE TECHNICAL ASSISTANCE CONFERENCE CALL

“Needs Assessment for Titles I and II”

SUMMARY OF PARTICIPANT EVALUATIONS

The subject of the tenth conference call in the Ryan White Technical Assistance Conference Call Series was Needs Assessment. On March 26th, 1996, 220 sites received basic instruction on conducting a needs assessment, and heard a sampling of diverse needs assessment experiences from grantees. The team of speakers included four members of the Division of HIV Services, three consultants, and six grantee representatives. The listening audience -- comprised primarily of Title I and II grantees and planning council and consortia members -- was the largest audience thus far for a call in this series.

Panelists.

From the Division of HIV Services (DHS):

1. Anita Eichler, Director, DHS
2. Andrew Kruzich, Deputy Director, Planning and Technical Assistance Branch, DHS
3. Wendell Pope, Service Documentation Branch. DHS
4. Steven Young. Chief, Eastern Services Branch. DHS

Contributing consultants:

1. Cristina Lopez, MOSAICA, Washington D.C.
2. Erica Salem, Consultant to DHS, Chicago
3. Donna Yutzy. Consultant to DHS, Sacramento, CA

Grantee Experiences:

1. Mo Lovely, Chair. Shasta-Trinity AIDS Consortium, Weaverville, CA
2. Susan Sachs, Piedmont Consortium, North Carolina
3. Diane Seyl, Ventura County Public Health Services. Ventura County. CA
4. Greg Thielemann, Professor of Political Economy at University of Texas at Dallas and Consultant to the Dallas EMA
5. Dr. Elizabeth Trebow, Manager Health Statistics, Ventura County Public Health Department, Ventura, CA
6. Joey Wynn, Chair, Joint Planning Committee, Miami Planning Council

Jon Nelson, Chief of the Planning and Technical Assistance Branch at DHS, facilitated the conference call.

This report is based on fifty-seven evaluations that were received from conference call participants during the several weeks following the call. While some listeners comment on the usefulness and timeliness of the conference call content, eighteen percent of respondents feel that too many speakers tried to cover too many topics. Thirty percent stress the importance of timely follow up report summaries. Twenty-three percent of respondents ask for more extensive materials prior to the conference calls, in order to prepare questions and follow along during the call.

Overall Evaluation of Conference Call:

1	2	3	x	4	5
Poor		Satisfactory			Excellent

Average Response: 3.6

Listeners regard the technical coordination and content positively, rating the overall conference call 3.6 on a scale of 1 to 5.

Suggestions or Comments Regarding this Conference Call

Listeners comment on the usefulness and timeliness of the conference call content, and commend its organization. Some appreciate the inclusion of speakers from rural areas, and ask that the conference calls continue to rely on actual grantee experiences to illustrate topics. However, eighteen percent of respondents feel that too many speakers tried to cover too many topics, causing the information to be presented too quickly and important topics to be skimmed over. Another repercussion is the lack of time available for questions from the listeners.

Eight percent of respondents feel that the conference call spent too much time on a general overview of needs assessment. Ten percent complain that the discussion of secondary data sources was too technical and difficult to comprehend.

Random comments and suggestions include the following.

- ◆ The general steps of needs assessment were well balanced with the specifics provided by the grantees.

- ◆ The conference call should have addressed the issue of limited staff available to conduct the needs assessment.

Recommendations for Follow up to this Particular Conference Call

Thirty percent stress the importance of follow up report summaries; of those, twelve percent ask that reports be produced and distributed faster. Respondents comment on the usefulness of the conference call reports in general. Some feel that since this conference call presented material clearly and emphasized important points effectively, this conference call summary will be a useful document. Others request that needs assessment tools and samples be made available through Project Officers.

Random recommendations include the following.

- ◆ Check to determine if this conference call assisted grantees in their needs assessment processes.
- ◆ Hold a question and answer session following the release of the report.
- ◆ Distribute the questions submitted for this call, with answers.
- ◆ Be sure to explain how to access all of the information mentioned in the conference call.
- ◆ Review sample needs assessments in a follow up conference call.
- ◆ Include the names and phone numbers of presenters in the report.

Recommendations for the Organization and Content of Future Conference Calls in this Series

Organization

A common request that emerges in the evaluations is the desire for more information prior to the conference call. According to respondents, sending copies of presentations in advance will promote interaction during the call by allowing listeners to review the information and prepare questions. Several listeners suggest ways to alleviate the feeling that too many speakers are covering too many topics. In the future, fewer speakers could cover fewer topics in more depth. or conference calls could be extended by a half hour.

Other organizational recommendations include the following:

- ◆ Hold separate conference calls by level of expertise. **and/or** resources available.
- ◆ Utilize teleconferencing options.
- ◆ Conduct a two or three part conference call series on one topic and produce a follow up workbook.

Content

Respondents make suggestions regarding content of future conference calls.

Suggested topics for future conference calls include.

- ◆ Managed care update and effect on conducting a needs assessment
- ◆ New DHS program policies and reauthorized legislation
- ◆ Quality assurance
- ◆ Illustration of sample Title I and II needs assessment processes

Actions for Improvement

In planning the upcoming conference call. scheduled for June 12th on issues of coordination between planning councils and consortia, we have incorporated suggestions indicated here. The format of the next call will be an interactive one, with fewer speakers and therefore, more time for questions from listeners. Hopefully, this format will address concerns regarding speakers rushing to cover too many topics.